

## Stopping a Silent Killer Bipartisan Legislation Introduced by Reps. Baird & Castle Could Help Save Thousands of Lives (July 23, 2008)

Washington, D.C. - Every year as many as 40,000 people die from pulmonary fibrosis (PF). That is enough people to fill Portland's Rose Garden Arena twice. The relentlessly progressive and ultimately fatal disease currently has no known cure; PF hijacks a victim's lungs, slowly making it impossible for one to breathe. Yet despite these appalling facts, very little is known about this disease. However, that could soon change, thanks new legislation introduced by Congressmen Brian Baird (D-WA-03) and Mike Castle (R-DE-at large). When passed, the bipartisan Pulmonary Fibrosis Research Enhancement Act. will direct more 15 million dollars to studying, and hopefully stopping this silent killer.

"We as Americans have walked on the moon, spliced the gene, and split the atom," said Congressman Baird. "Together we can find the cause of, and cure for this dreaded disease. It only takes 3 things: creativity, courage, and cash."

Finding a cure for PF is a cause that hits especially close to home for Congressman Baird; his father passed away from the disease in early 2001. A life long teacher, and World War II Veteran, William Baird was the picture of health until 1999, when at 71 years old he went to the doctor complaining of shortness of breathe. It was then when both father and son learned of pulmonary fibrosis for the first time. They also learned the diagnosis was a death sentence.

Reps. Baird and Castle have been working closely with the Coalition for Pulmonary Fibrosis (CPF) to create a bill that will be the first of its kind to improve research and awareness of this deadly disease with no known cause, cure, or even treatment.

"Pulmonary Fibrosis kills almost as many people as breast cancer annually, yet public awareness and medical research lag far behind," said Rep. Castle. "PF is an ultimately debilitating and fatal disease, and one that has taken several people very close to me. We can accelerate research funding at the National Institutes of Health and create a registry system to identify the cause and progression of the disease, in order to find new and better approaches to treat and cure PF."

According to the CPF, as many as 120 thousand people in the United States could be living with PF and not even know it. Research has shown the disease is more prevalent in men than in women, and most often occurs in people between the ages of 50 and 70. Life expectancy after diagnosis is usually less than 4 years.

"Every 13 minutes, someone's family member loses a battle with PF, yet most hear about it for the first time when they're diagnosed; that's simply unacceptable," said Baird.

"It is compelling to see these strong leaders come together to fight for a disease that knows no boundaries and can attack anyone," said Mishka Michon, Chief Executive Officer for the CPF. "Their show of support is so uplifting to the PF patient community and the researchers who are working so hard to find answers and treatments for pulmonary fibrosis and we are all grateful. We look forward to the successful passage of this legislation."

Cosponsors of the Pulmonary Fibrosis Research Enhancement Act include Reps. Nathan Deal (GA-09), Jim Gerlach (PA-6), Mark Kirk (IL-10), Marcy Kaptur (OH-9) Steve LaTourette (OH-14), Bill Young (FL-10), Jane Harman (CA-37) and Jackie Speier (CA-12).

When passed the Pulmonary Fibrosis Research Enhancement Act will:

Encourage expanded federal research on PF at the National Institutes of Health (NIH)

- The Pulmonary Fibrosis Research Enhancement Act will encourage NIH to intensify and coordinate activities to understand, treat, and cure PF.
- Create the first National PF Registry
- The national registry will improve data collection and information sharing in order to move the research forward more quickly. This effort will be lead by an advisory board comprised of government agencies, patients and their advocates, and clinical experts and scientists. The Registry will expand upon existing data and will be made available to the NIH and the Department of Veterans Affairs.
- Create a National PF Action Plan
- The Pulmonary Fibrosis Research Enhancement Act will direct the Centers for Disease Control (CDC) to work with the Advisory Board to prepare a comprehensive Action Plan for pursuing a cure for PF and addressing the costs and burden of pulmonary fibrosis.

- Call for a National Summit on PF

- The Pulmonary Fibrosis Research Enhancement Act will call for a summit of researchers, representatives of academic institutions, federal and state policymakers, public health professionals, and representatives of national voluntary health organizations to be convened one year after enactment of the bill and every 3 years thereafter in an effort to provide greater coordination on PF research and prevention.

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